Discussion of Major Issues

There are many issues that can be identified when examining barriers to American Indian research and research training. The following is a summary of the major issues discussed by the participant of the Roundtable.

Issues of Credibility with American Indian Community

Lead Discussants:

Lillian Tom-Orme, PhD, MPH, *Huntsman Cancer Institute*
Linda Burhansstipanov, PhD *Native American Cancer Initiatives, Inc.*
Marlene Jasperse, PhD, *Navajo Nation Division of Health*

Despite great interest within American Indian and Alaska Native communities regarding the benefits of biomedical research and deep concern for Tribal health, distrust of researchers and NIH-funded research project remains. This distrust has been reinforced by repeated cases of research being conducted in Indian communities without the full knowledge and participation of the community. Further, researchers from outside Indian communities have often lacked knowledge of and sensitivity to Tribal cultures and structures. Many Indian communities still remember unpleasant experiences with anthropology based research in the early 1960's and 1970's. More recently, concerns have been raised regarding genetic research, acquiring consent for study participation, formulation of study questionnaires, and the collection, storage and disposal of human specimens.

Concern has also resulted from data collection and interpretation. Errors recording patient race in general studies, for example, have been shown to underrepresent American Indians/Alaska Natives. The Indian Health Service routinely adjusts vital statistics on American Indian mortality data from certain states where racial misclassification remains a problem. Data that has been collected in studies specific to American Indian and Alaska Native communities, such as the Survey of American Indians and Alaska Natives (SAIAN), regularly do not include Indian participation in the interpretation of data. This has led to misinterpretations of the true meaning of participant responses. Meanwhile, data collected within a specific Tribe has been used to describe the health status and priorities of American Indians/Alaska Natives in general. For example, the Surveillance, Epidemiology, and End Results (SEER) data from National Cancer Institute were gathered in the Arizona, New Mexico "Four Corners" area. Applying the results of such studies in areas that face very different health issues tends to oversimplify the true nature of American Indian/Alaska Native health. The credibility of Indian related research can be substantially improved by developing and including Native American researchers.

In response to this historical lack of inclusion, most tribes have instituted Institutional Review Boards (IRB's). Communities have begun to question how researchers will protect data, what liabilities are involved, how the community will benefit from the research, and what assurances exist to ensure long-term involvement by researchers in the community. In addition, communities have asked to be consulted and to have beliefs respected with regards to study protocol, instrument and sampling.

These internal developments have begun to shift control of research policies and priorities to Tribes as sovereign nations. However, a need continues to exist for changes in the NIH and investigators conducting Indian research. Work to develop trust between the NIH research community and Indian communities can look to successful, community-based projects that have been initiated by Indian scientists. In these cases, researchers have sought to understand and partner with the local community. They have spent time with community representatives on-site, attended Tribal Council meetings, discussed proposed research, answered questions and maintained a long-term presence in the community. Indigenous researchers can build important bridges between the research and Indian communities. An example is the effectiveness of a Navajo researcher speaking Navajo to describe a project for approval of the governing body.

An example of this approach is the Native American Cancer Researcher Training Program. The Principal Investigators in this project have gained a great deal of credibility by showing commitment in the community over many years. They have included and developed local talent through hiring, equipping and training members of the community to participate in health care prevention, administration and research programs. Researchers developed project protocol, instrument and culturally sensitive questions at the local level. The investigators have demonstrated that their research is relevant to Tribal health concerns and that the individuals conducting research have long-term commitment to the project.

Finally, with respect to building credibility, the NIH research community needs to understand the health and research needs of American Indian and Alaska Native communities from the perspective of these communities. Considering the holistic, spiritual and serious manner in which Indian communities deal with illness would be an initial step. Looking to underlying factors, such as poverty, poor housing, unemployment and other socio-economic problems that may challenge healing and cause changes in health status, would be another important consideration. Lastly, patient education, regarding the true nature of a particular disease, is an essential counterpart to understanding community health perspectives and building trust with Indian communities.

Needs of New Basic Science Investigators

Lead Discussants:

Gilbert John, PhD, *Oklahoma State University*
Wilfred Denetclaw, PhD, *University of California, San Francisco*
David Burgess, PhD, *Boston College*

One of the critical issues facing new basic researchers and young faculty from American Indian and Alaska Native backgrounds is that they very often live in two diverse worlds -the research world and the world that includes their family and Indian culture. Young Indian researchers in faculty positions frequently sense that their attempt to attain tenure in a university setting is in direct conflict with their commitment to their cultural ties. When choosing to conduct their research within Indian communities, Indian researchers have faced perceptions from others in the field that their work is not as rigorous or broadly applicable as non-minority research. They report the more prestigious journals are less likely to publish minority-focused research. This gap between what is considered "minority research" and general "academic research" affects Indian faculty in their path to tenure and increases the difficulties of living in two worlds.

Additionally, most universities are so delighted to have a minority faculty member that they overwork them, assigning them to multiple task forces and committees. Often being the only American Indian/Alaska Native on campus, they lack role models while simultaneously being looked to as a role model and mentor by Indian students on campus. New researchers and faculty feel compelled to serve as mentors. However, this raises concerns that the time dedicated to mentoring is rated in a disproportionately low manner in tenure considerations. Thus, pressures on new Indian researchers and faculty are high, yet much needed support is generally lacking.

An approach to help support new American Indian and Alaska Native faculty and researchers must include several basic components. First, these programs should reward faculty for mentoring students. The potential exists to reward mentoring in both tenure track decisions and through monetary compensation on a per student basis. Secondly, successful support programs should offer mentoring to faculty themselves. Model pre-college bridge programs can be used to develop such programs at all levels–community college to research institution, four-year program to PhD, and PhD to junior faculty. NIH could work in this arena to provide comprehensive mentoring support of new Indian faculty. Assistance in grant writing could go beyond workshops on how to write grants to being better represented on fellowships or AREA review panels as reviewers. Finally, a number of non-profit organizations provide opportunities for Indian faculty/researchers to meet together, creating support networks that combat the potential isolation of their individual institutions. This comprehensive approach to mentoring could provide important support to new, young Indian researchers.

Medical Doctors and Professionals Who Want to Do Research

Lead Discussants:

Yvette Roubideaux, MD, MPH, *Director, American Indian Physicians Association, Deputy Director, Center for Native American Health, Clinical Assistant Professor, University of Arizona*

Judith Kaur, MD, *Mayo Comprehensive Cancer Center*

Jeffrey Henderson, MD, *Strong Heart Study – Dakota Center*

There are a number of barriers for American Indian medical doctors entering clinical research. M.D.'s often decide to become researchers later in life and thus have career change challenges compounded by a lack of previous training in research methodology. They often lack role models and collaborators, face a negative attitude in the community towards research, and are located far from research institutions.

At the same time, M.D.'s have unique insights into the health needs of the community. They are very aware of the need for particular data and its importance for starting new programs. In addition, they have a patient-oriented view that leads to many research questions. And, finally, they can serve to educate their patients about the value of research. In this way, M.D.'s are in a position to be the vital link between research and patient care, yet they need more support to successfully transition into the role of researcher.

One example of support and mentoring for MD's making this career change is the American Indian/Alaska Native Research Network. This internet-based resource includes 151 Indian researchers. Through the Network, they access training and technical support in survey methods, grant writing, sampling and more. Students, who are interested in research, can also access the Network for information and contacts.

Encouraging and Engaging Students– What Has Worked

Lead Discussants:

Clifton Poodry, PhD

James Jarvis, MD, *Department of Pediatrics, Oklahoma University Health Sciences*

Sandra Begay-Campbell, *Executive Director, American Indian Science and Engineering Society*

Judit Camacho, *Society for Advancement of Chicanos and Native Americans in Science*

Spero Mason, PhD, *University of Colorado Health Science Center*

Judith Gobert, PhD, *Salish-Kootenai College*

Sophia Cleland

Example 1: Initiative for Minority Student Development (IMSD), under a grant from the Minority Biomedical Research Support (MBRS) program.

At the University of Montana, students participated in a very different type of learning experience during their summer project. Rather than place the 12 freshman students in a lab, they researched diabetes to create a web-based learning module. Each student learned about an aspect of diabetes and taught it to her/his fellow students. The group then worked together to develop an interactive web-site which turned their research into a captivating and understandable explanation of diabetes. Through this project, students learned not only about diabetes, but also about group process, web-site development, writing and editing. In addition, they have come away committed to the health of their community.

Example 2: Headlands Indian Health Careers program at Oklahoma University

The main tenet of this program is to get students interested in research by involving them in seeing what research can do. In this program, students work once a week in the clinic with patients, in addition to their work in the lab. This gives students a context for their lab work and a more holistic understanding of the benefits of research. However, to truly support students in pursuing research careers, they need to be funded to work at a lab over several summers, rather than only one. To keep students excited about research, ways need to be developed to ensure that the students stay involved.

Example 3: American Indian Science and Engineering Society (AISES)

Over its twenty year history, AISES has learned several things about mentoring students. The main lesson has been that it takes time to mentor. Students need to be supported well before they enter college. The key investment is time.

The next phase of work is to focus on developing faculty and other role models today and for the future. A part of mentorship, then, is to instill a dedication to give back to the next generation. Another important piece of AISES' work is the annual AISES National Conference that allows members to get together on a yearly basis with colleagues.

Example 4: Society for Advancement of Chicanos and Native Americans in Science (SACNAS)

The 26-year-old mission of SACNAS is to promote students into PhD programs in science. Through the organization's web-site and journal, SACNAS News, SACNAS provides role models, practical guides to choosing a career and tools to follow that path. In addition, SACNAS partners with institutions and professional organizations to offer opportunities for students, such as Mathematical and Theoretical Biology Institute (MTBI), Summer Institute in Mathematics for Undergraduates (SIMU), summer internships and the Neuroscience Scholars Research Program. SACNAS, like AISES, has found that meeting at the organization's annual national conference is a vital part of the process of mentoring students. The organization strives to have as many individuals involved as possible to be mentors in applying to graduate school, writing successful grants and learning about research that is being done. During the national meeting, students have the opportunity to present their science research and have it reviewed by faculty and peers.

The fruits of the labor have born out; students from 20 years ago are now faculty, who continue to be dedicated to giving back to their communities.

Example 5: The Native Elder Resource Center (NEHCRC) at the University of Colorado

NEHCRC programs range from mental health to tele-medicine. With 110 interdisciplinary staff based in Denver and six field offices, this project works with 29 reservations and rural and urban collaboration sites. The four functions of this project are research, training, information dissemination and technical assistance. The Native Elders Resource Center is an example of a training opportunity that works. There are four cores in this center. Utilizing state-of-the-art telecommunication, the Community Liaison Core conducts ongoing studies, conducts town hall meetings and works with local advisory committees. The Investigator Development Core is a two-year training program with three American Indian/Alaska Native investigators. The Investigator Development Core participants must have seven or less years of post-general work.

NEHCRC has learned that the keys to encouraging and engaging students include a history of high quality research, strong institutional support and involvement and a critical mass of experienced investigators from a wide range of disciplines. American Indian and Alaska Native scientists who serve as role model must be well published, experienced at mentoring and have connections to potential sponsors.

The program seeks to promote self-reflection, coupled with the ability to hear other perspectives and accept constructive criticism. Emphasis is placed on writing skills and adequate scientific preparation in concrete, personally relevant terms. They work to demystify the grantsmanship process, restructure discouraging circumstances as challenges, and teach recognition of, and response to, tension with peers or professors.

Example 6: Salish-Kootenai College – Tribal College in Montana

The majority of American Indian and Alaska Native students attend community and Tribal Colleges rather than a four-year research institution. Yet, few resources are in place for research or research training at Tribal Colleges and little research has received NIH funding at these sites. For students of Tribal and community colleges the

results of this are double. Receiving limited background in contemporary science or research oriented studies inadequately prepares them to enter research institutions. In addition, the lack of viable research programs at the community/Tribal college level, minimizes potential student interest in a research career.

The Salish-Kootenai Tribal College in Montana has developed a high school to Tribal College bridge program, followed by a tribal college to university bridge program. This program has shown a 93% success rate in taking high school students to high-tech industry and to engineering school. The pedagogical approach includes hands-on learning and an integrated curriculum in a cooperative environment with high standards of achievement.

Example 7: National Indian Honor Society

Begun in 1981 by Frank Dukepoo, PhD, the Society has motivated 2,500 students at the pre-college level to achieve their highest ability, graduating high school with straight A's. The summer program of the Society has had a 100% retention rate over the last three years. By making a long-term investment at the lower grade levels, students develop a positive attitude about their potential to excel.